Talking About Baby K's Fate

by Giles R. Scofield, J.D.

The case of Baby K reminds me of Shirley Jackson's short story, "The Lottery," in which a community swarms around one of its members and stones her to death. According to the community's beliefs, her number had come up. Her fate now rested, quite literally, in the hands of the community.

So, it seems, does Baby K's. An array of forces, including the American Academy of Pediatrics and the Society of Critical Care Medicine, believes that it is time for Baby K to die. Opposed to this perspective is the position taken by the Department for Rights of Virginians with Disabilities, which is that we cannot countenance the destruction of lives of those who are, for whatever reasons, not worthy of continued existence.

Caught between these positions are Baby K and her mother. Baby K is neither aware of what is going on nor responsible for turning her medical case into a federal one. She is gradually dying of complications related to her anencephaly. Her mother has one view of when Baby K should die; Baby K's physicians have another. For some reason, conversation about this matter has deteriorated to the point that the hospital has invoked judicial assistance. The Court of Appeals, applying a somewhat obscure federal statute in a way that is consistent with its language and apparent intent, has ruled that it would be wrong to deny Baby K emergency medical treatment.[1]

I am less troubled by that ruling than I would have been had the court endorsed the position presented to it by the hospital in question. Although I probably would not have made the choice Baby K's mother did and certainly would not have done so for the reasons she did, I do not regard her choice as clearly wrong. I do think it would be a mistake to regard her decision as intolerable. Certainly we can allow some latitude and room for disagreement where decisions about death are concerned.

Yet, as the briefs and articles surrounding the case of Baby K suggest, this case raises apocalyptic visions in the minds of some. On the one hand, if we are not allowed not to treat Baby K then the forces of unbridled patient autonomy will turn the physician-patient relationship on its head and jeopardize any effort at healthcare reform. On the other hand, if we countenance a decision not to treat Baby K we will no longer be a society that believes in the inalienable right to life, but become one that believes that some lives are not worth living.

In these circumstances we would do well to recall the cautionary wisdom of the President's Commission, which observed that the empty rhetoric surrounding life-and-death matters tends to obscure the issues at stake and to impede our ability to deliberate.[2] Baby K is another case in which the rhetoric of rights disserves us, in several ways. First, it suggests that it is possible to resolve this tragic choice in a way that demonstrates unswerving allegiance to the fundamental values at stake. And the one thing that makes these choices "tragic" is that they force us to acknowledge that we must decide them by expressing a preference for one value, but without marginalizing or trivializing any of the competing interests at stake.

Second, the rhetoric of rights forecloses the possibility of conversation.[3] Rigid, simplistic assertions about what the concept of medical futility or the prohibition against discriminating against the disabled must mean in this case prevent us from talking about what those concepts may or do mean in this case. They reduce a conversation about what ought to be done into a war of slogans, as if moral jingoism were a substitute for serious discourse.

And because conversation is the essence of consent, and consent the concept on which society's political, legal, philosophical and moral structures rest, our inability and unwillingness to converse imperils our commitment to democracy. The case of Baby K demonstrates not only that it is futile to expect "modern" concepts to resolve "post-modern" dilemmas, but that it is dangerous to do so. If we must "converse or perish,"[4] then the case of Baby K challenges us to learn the lost art of conversation. To do that, we must see that this case is both simpler and more complex than we are led to believe.

Medical futility, medical power

Some contend that we can resolve the case of Baby K by applying the concept of medical futility. Under this line of reasoning, doctors are not obligated to render medically futile treatment. Baby K's mother is seeking treatment that is medically futile. Therefore, she has no legitimate right to demand this treatment and the hospital and physicians may rightfully refuse to render this treatment without fear of liability.

Before seeing where the problems lie here, let's acknowledge where difficulties don't exist. It is beyond dispute that doctors and hospitals are not obligated to render and cannot be held liable for failing to render futile treatment. I suspect that if we were to ask whether Americans think that they have a right to receive, that doctors must

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provide or that the government should pay for treatment that does nothing for them, they would say "no." Thus, the debate is not over what the principle is, but about how to define and apply the principle. And that's where things break down considerably.

The problem with the concept of medical futility is that it is a lot like pornography. No one can define it, but everyone claims to know it when they see it. Defining medical futility has proven so difficult that some have abandoned the hope of doing so, and have argued that we should place our faith in such concepts as "medically non-beneficial" or "medically inappropriate," as if they possessed the clarity of meaning that medical futility lacks.

Second, nothing suggests that physicians can or always do make medical futility judgments reliably, accurately, fairly or objectively. Medical futility is an impression, not a measurement, and impressions are susceptible to subjective variation--bias and prejudice--in a way that measurements are not. In definition and application, then, medical futility is value-laden, not value-free. Thus, even though I suspect everyone would agree that it is medically futile to treat a dead person, we do treat the dead if we think their organs are worth salvaging. For these reasons, it is wrong to regard medical futility as if it were a scientific concept, some neutral arbiter of what ought to be done.

If nothing supports the belief that physicians can make judgments about medically futile treatment scientifically and objectively, how much truth is there in the belief that patients and families cannot participate in these decisions? Not much. To the extent that anyone has bothered to study the issue, they have discovered that the vast majority of patients and families will agree with a physician's recommendation about medically futile treatment, especially when that recommendation is communicated clearly and sensitively. Thus, consent works; it's not an obstacle to practicing medicine professionally.

The fact that some patients and families may disagree with their physician's judgment is hardly reason to disenfranchise all patients, especially given the fact that physicians themselves will disagree about what is and isn't medically futile. Some families and patients may take longer to see things from the physician's perspective; given that the physician has seen more and that families have to come to grips with an uncomfortable realization, this disparity is understandable. The fact that a few will never see things as their physician does does not justify denying everyone the opportunity to come around. Insisting on the absolute right of physicians to act on judgments about medical futility makes sense only if we believe that we cannot tolerate differences of opinion where decisions about when death should occur are at stake. This amounts to saying that we must have uniformity of opinion in such decisions, which we won't get anyway since physicians themselves are not uniform in their beliefs about what medical futility means or when it should be applied.

Others argue that denying physicians the ability to act unilaterally with respect to medically futile treatment prevents us from reforming the healthcare system. Granting physicians this authority, on the other hand, will enable us not only to set limits to health care, but to allocate resources more sensibly and expand access to care. If you believe this argument, then you must also believe that if we eliminate corporate waste in the oil industry, everyone will get better gas mileage and we'll have good public transportation. It doesn't work that way.

Apart from the fact that this viewpoint suggests that patients created the healthcare industry, which they did not,[5] or that all patients are demanding to be resuscitated to death, which they are not (I have trouble imagining Baby K as a "demanding" patient), this argument is simple nonsense. If my physician is granted the right to deny me medically futile care, exactly how and why must my private insurance carrier improve its benefits package or start covering the uninsured? A decision to deny some forms of treatment to certain individuals is not a decision to offer additional benefits or to provide universal access.

If there is a relationship between medical futility, resource allocation and access to care, it is the opposite of what medical futility's apologists make it out to be. If we were to decide to provide universal access to care, we'd be forced to decide what sort of benefits it makes sense to provide and to set limits on the conditions under which some treatments would be available. Thus, if we truly want to do something about medically futile care, we must start by expanding access, not by setting limits. Appeals to justice and sensibility make sense only in a society that has an equitable, sensible healthcare system, which ours is not.

Others argue that we demean medical professionalism if we compel medical professionals to act against their better judgment and to render treatment under circumstances that they regard as inappropriate. If we wish physicians to behave professionally, which means seeing that they not behave unprofessionally, we must allow them the right to deny patients medically futile care. This argument appeals to the professional identities of medical ethicists and others, who, by and large, have responded by showing their professional solidarity, which finds expression in the many arguments devised to support the physician's right to deny patients medically futile care. Here again, I suspect that patients agree that physicians should behave professionally and should not behave unprofessionally. This only begs the question about what it means to do the one and not the other.

If physicians wish to behave professionally where decisions about medically futile treatment are concerned, then they should share their knowledge with patients and families, not conceal it, especially given how uncertain and variable that knowledge is. If they think it is unprofessional for any physician to initiate or render medically futile treatment, then they should agree with the following propositions: 1) no patient, family or provider should pay for such treatment; 2) patients who undergo such treatment should be compensated (as should family members who look

on in anguish; and 3) physicians who initiate or continue such treatment should be subjected to credentialing and licensure actions for having engaged in unprofessional conduct.

Oddly, one doesn't hear those who think there is something unprofessional about rendering medically futile care arguing in favor of these propositions, even though each is consistent with every profession's stated desire to protect the public's interest and to rid itself of unbecoming professionals. What you **do** hear is the claim that doctors should enjoy preemptive immunity in this aspect of medical decision-making. That view is more consistent with protecting medicine's self-interest than with looking out for the welfare of patients or the public. Thus, the argument that professionalism is at stake does not withstand scrutiny.

Finally, there's the argument that consent counts only when doctors intend to violate a patient's physical integrity, not when they wish to refrain from doing so. This argument is wrong for two reasons. First, it ignores the concept of informed refusal. Second, it ignores the other values that the consent process concerns itself with. Those are: 1) respecting the patient's human dignity; 2) encouraging professional self-scrutiny; 3) fostering shared decision-making; 4) avoiding deceit and coercion; and 5) educating the public. Conversation fulfills those goals; silence does not.[6]

The arguments that support a doctor's "right" to deny patients medically futile treatment can best be described as the rhetoric of reaction.[7] They ask us to believe not only that consent is futile where futile treatment is concerned, but that the healthcare system will be jeopardized and the physician-patient relationship turned on its head if patients are allowed to have any say in decisions about medically futile treatment. Having already addressed the first two points, let me say that the last can be true only if one believes that the natural order of the physician-patient relationship exists when the physician is dominant and the patient is subordinate. Such a view of the physician-patient relationship is inconsistent with the ideal of shared decision-making between equal participants.

What this means, then, is that the real argument is about how power is to be distributed within the physician-patient relationship. If power is defined as "the probability that one actor within a social relationship will be in a position to carry out his will despite resistance, regardless of the basis on which this probability rests" or as the ability to act without fear of impunity, then the rationale that best ties together the arguments made in favor of allowing physicians to act unilaterally where medically futile treatments are concerned is the desire to protect medical power in an age of constraint. If we wish to grant physicians this power, we need to consider what it means.

Anyone who knows anything about medical decision-making is familiar with two basic tenets. First, decisions to withhold and withdraw treatment are legally and ethically the same. Second, we cannot deny incompetent patients rights that competent patients possess. Because of the transitive nature of these concepts, allowing physicians the "right" to withhold medically futile treatment means that they have the right to withdraw it, too. And, it means that they may do so in instances involving competent as well as incompetent patients.

This being the case, the decision to litigate medical futility in the context of incompetent patients reflects sound strategy and tactics. After all, were any physician or hospital to litigate the right to deny medically futile care to a competent patient, we would be outraged at the attempt to deny care to a sentient, talking being. By raising the issue in the case of incompetent patients, doctors and hospitals can portray themselves as sensible and rational and portray patients and families as insensitive and irrational. It helps medicine's cause to pick patients whose treatment is fully paid for, to rid themselves of the accusation that they are acting out of self-interest, to focus on such desperate cases as the permanently unconscious and anencephalics, because no one would want to be "like that," and to play up the religious motivations of family members, which plays into the prejudice that many Americans harbor about religion.[8]

Although I understand why physicians feel the need to make these decisions unilaterally, I wonder whether they want to do so. For starters, it is an awesome responsibility, especially if the patient is competent. For another it creates a way of handling end-of-life decision-making that perpetuates the practice of psychologically abandoning dying patients. As Sherwin Nuland has so poignantly observed, the worst way to die is in ignorance and isolation, without solace, comfort or the human touch that only humane practitioners can provide.[9] I say this because if one thing is true where physicians and patients are concerned, it is that every physician will one day be a patient. And physicians who are or have been patients draw from that experience the insight that doctors should order less and talk more.

It's for reasons such as these that consent, by which I mean conversation, needs to be obligatory, not precatory. We have allowed exceptions to the rule of conversation only where and because it is impossible to talk with the patient as in an emergency or when the patient is unconscious, not when or because it is inconvenient or inexpedient to do so. If we carve out an exception for medically futile treatment, out of some belief that consent can be dispensed with or stands in the way of what we need to do, we jettison the process designed to "get in the way" of our actions and deprive ourselves of the conversations we must have if we are to understand what we are doing and why.

Persons and disabilities

If the advocates of medical futility raise troublesome arguments, so, too, do those who portray themselves as disability advocates. Although they are right to raise our consciousness about the extent to which prejudice about disability affects decisions made concerning persons with disabilities, their approach to these cases is not free of prejudice. The question here is not whether anyone wants to discriminate

against persons with disabilities (no one would admit to that), but what it means to do so. This is where the issue becomes more complex.

Prejudice influences how we perceive and behave with respect to others, including persons with disabilities.[10] It may be reflected in beliefs about what it must be like to live "like that" or in stereotypes about how such persons do or should behave. Unless we believe ourselves to be free of prejudice where persons with disabilities are concerned, we cannot rule out the possibility that prejudice affects the decisions we make with respect to this group and to individual members of it. This awareness and sensitivity is central to reconciling our need to set limits to health care, at the societal and clinical levels, in ways that do not demonstrate diminished respect for persons with disabilities. The question we face is not whether we can make these decisions, but how best to make them, given that we must.

In fact, disabilities advocates are neither consistent nor logical in their position. For example, in Baby K they endorse the idea of family decision-making, the very idea they opposed in the *Cruzan* case. Family decision-making, it seems, is valid only if the decision the family makes is correct in the eyes of others. Moreover, if we discriminate against the disabled any time we deny someone a benefit that would enable him or her to live with a disability, then shouldn't we outlaw Do-Not Resuscitate (DNR) orders altogether? After all, someone might survive CPR with a neurological deficit, i.e. a brain injury. And if there's something wrong with not treating someone merely because they already have a head injury, isn't it just as wrong to deny someone the opportunity to become a person with a disability? And why aren't disabilities advocates filing lawsuits every time an elderly patient is placed on a feeding tube when he or she is suffering from dysphagia that can be less aggressively treated? Or working to reform the conditions under which disabled prisoners are treated? Or filing suit any time a rehabilitation hospital denies admission to a disabled person? Mainly because the mission of many so-called disabilities advocates is not to improve the lives of the disabled, but merely to extend them, an ethos that does not square with that held by those who work in the field of physical medicine and rehabilitation. To see just how misguided the simplistic approach to advocating on behalf of persons with disabilities is, we need only examine the trial court's opinion.[11]

In Baby K, the trial judge rested his decision that Baby K should be treated on two propositions. The first is that to render treatment would not deny Baby K of a benefit to which she was otherwise entitled. The second was that a decision to render treatment would not discriminate against persons with disabilities. Neither belief stands up.

The decision to render treatment to Baby K denies her, for the time being, hospice benefits. Thus, any decision to confer one benefit necessarily constitutes the denial of another benefit. The denial of this other benefit can be valid only if it is a benefit that a disabled person is not otherwise qualified for. And to believe that a disabled person does not qualify for the benefits of hospice care is to believe that persons with disabilities are supposed to live and die a certain way. This attitude reflects a stereotyped perspective about persons with disabilities, which means that its endorsement creates and perpetuates prejudice concerning persons with disabilities. For this reason, it cannot be said that Judge Hilton's decision does not discriminate against Baby K and does not perpetuate prejudice about persons with disabilities.

If it is somehow prejudicial to base a decision not to treat a patient on the belief that no one could, should or would want to live "like that," it is just as prejudicial to base a decision to treat such a person on the belief that no one could, should, or would want **not** to live "like that." Each perspective presumes to know what someone "like that" would or should, which means that each perspective traps persons with disabilities within the beliefs other have about them. And this means that no scheme of decision-making that rests on either perspective can claim to be free of prejudice or not to discriminate against persons with disabilities.

This leaves us in a dilemma. We wish to make these decisions in ways that assure us that we are not guilty of perpetuating prejudice, but find that decisions to treat and decisions not to treat are equally vulnerable to that accusation. Given that we must make these decisions, and given that we cannot find solace so long as we do this or do that, we are left with one option: we must pay close attention to **how** we decide these cases.

How do we do that? For starters, it would help us to see what prejudice against persons with disabilities is and is not like. And the place to start that is with Judge Hilton's ruling. Judge Hilton believed that the decision to deny Baby K emergency treatment was wrong because it was a benefit for which she was otherwise qualified. The phrase "otherwise qualified" has been adopted from other civil rights legislation, and is intended to see that individuals who are seeking employment or housing for which they are otherwise qualified are not denied those benefits on account of their race, sex or disability.

The problem with applying this phrase in the context of a decision about providing medical treatment for a person with a disability is that it does not make sense. The only way in which it could make sense would be if it were so that the disabled are denied benefits that able-bodied persons are enjoying. It is as difficult to imagine an able-bodied person demanding to be put on a ventilator as it is to suppose that refusing to provide ventilator support to someone who is able to breath independently denies that person a benefit.

While prejudice against persons with disabilities is similar in that it reflects the sort of prejudice that other groups, blacks and women, for example, have been subjected to, it is different in one respect. While race and sex are conditions of birth, disability need not be. Thus, while it is not possible for a white person to slip into being black, or for a man to slip into being a woman, it is possible and likely that every able-bodied person will one day be disabled.

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Annual Seminar in Narrative Bioethics. Last year's seminar was led by Warren Reich of Georgetown University. Other leaders included Howard Brody, Michigan State, and Kathryn Hunter (Northwestern). It offered an inductive, narrative-based approach to bioethics. A similar seminar is being planned for 1994. Approximate cost, including room, board and materials: $850.00. For information, contact: Center for Literature, Medicine, and the Health Care Professions, Mahan House, Hiram College, Hiram, Ohio 44234. Phone: (216) 569-5380.

August 8-12, 1994. Health Care Issues in Pluralistic Societies. Sponsored by The International Program in Bioethics Education and Research. This European Bioethics Seminar is primarily directed to health care providers and teachers in the area of ethics, philosophy and theology. Special attention will be given to European traditions in health care ethics. The seminar is designed (1) to provide the participants with both a theoretical and practical understanding of contemporary and pressing issues in bioethics and (2) to educate the participants on a range of topics and problems that are the focus of current debates, both within health care institutions and in society at large. For more information, contact: I.G. van der Heide, M.A., Dept. of Ethics, Philosophy & History of Medicine, Catholic University of Nijmegen, P.O. Box 9101, 6500 HB Nijmegen, the Netherlands. Phone: 31-0-80-615320/ 617079. FAX: 31-0-80-540254.

August 11-12, 1994. The Third Annual Chicago Conference on Ethics in Healthcare Institutions. Sponsored by Loyola University in Chicago and cosponsored by the Park Ridge Center for the Study of Health, Faith and Ethics, the Institute of Medicine of Chicago and the Chicago Clinical Ethics Programs. For further information, contact: The Center for Ethics (Health Care Conference), Loyola University Chicago, 6525 N. Sheridan Rd., Chicago, IL 60626; Phone (312) 508-8349; Fax: (312) 508-2292. ■

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To the extent that we harbor prejudices about or discriminate against persons with disabilities, we end up perpetuating beliefs and practices that each of us will one day likely be subjected to. In the same way that the medical futility debate challenges physicians about how they would like to be treated when they become patients for whom treatment is futile, the disability debate challenges each of us to ask how we would like to be treated on the day that we become disabled.

What links each of these controversies is a simple truth: that life ends in death. If a disability is something that impairs or limits any human function, then death is a disability. And if anything renders treatment futile, death does. Therefore, when we talk about how we should decide the fate of persons for whom treatment is futile and persons with disabilities, we are, in effect, deciding how we want our fate to be decided when it becomes our turn to die.

Can we talk?

Given that we must make these decisions under conditions of empirical and conceptual uncertainty, the real question is how we can do so. Moreover, the real challenge is whether we can do so in a way that gives expression to what consent is supposed to be about and that enables us to distinguish discriminating from discriminatory judgment. No one rule can do that. We must engage ourselves in an edifying, ongoing conversation about what we are deciding and why. This requires that we regain the lost art of conversation, which is the essence of consent.

Alexander M. Capron has written that the informed consent process, as noted above, is supposed to: 1) encourage respect for human dignity; 2) encourage professional (as well as personal) self-scrutiny; 3) promote shared decision-making; 4) avoid deceit and coercion; and 5) educate others. While this model of consent may not contain all the elements a conversational approach requires, it is difficult to imagine how meaningful conversation can occur absent attention to the concerns this model addresses. If we are to sort out and learn to live with our differences, we must find a way to do this without going to court. The question we face is not whether we should or must converse, but whether we have the ability and willingness to do so. The choice--to converse or to perish--is ours to make.

ENDNOTES:

1. *In the Matter of Baby K*, Nos. 93-1899, 93-1923, 93-1924 (CA4, February 10, 1994).

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5. Starr P. *The Social Transformation of Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry.* New York:Basic Books, 1982.

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8. Carter S. *The Culture of Disbelief: How American Law and Politics Trivialize Religious Devotion.* New York:Basic Books, 1993.

9. Nuland S. *How We Die: Reflections on Life's Final Chapters.* New York:Alfred A. Knopf, 1994:243.

10. Allport GW. *The Nature of Prejudice.* Reading, MA:Addison-Wesley, 1954.

11. *In the matter of Baby K*, 832 F. Supp. 1022 (E.D.Va. 1993).

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